Identifying Barriers to Accessing a Pediatric Pain Clinic:
A Quality Improvement Project

Afton Potter

OHSU School of Nursing

NURS 703 – DNP Project

Dr. Katherine Bradley

September 3rd, 2021

Author Testimony

Submitting this assignment confirms this is the sole work of the author as required by the student code of conduct

Abstract

Up to 46% of children worldwide have chronic pain. Estimated costs to treat this in the United States is 19.5 billion dollars. Existing access barriers related to geography, gender, race, and socioeconomic status contribute to this cost. Efforts to remove access barriers can reduce the cost of pediatric chronic pain as well as improve patients' quality of life. This quality improvement project aimed to gather baseline data from a single pediatric chronic pain center that would identify removable access barriers and provide recommendations for practice improvements.

The Anderson Behavioral Model of Health Services Use served as a theoretical framework to support how existing access barriers identified in the literature drive how patients in the pediatric chronic pain utilize available services.

A retrospective longitudinal electronic health record (EHR) review of two sets of quantitative data over 5 months was performed. 8 patients were identified in a pre-covid data set (2019-20) and 14 patients a post-covid data set (2020-21). EHR were reviewed to determine mean follow-up rates for patients within the following categories: geographical location, gender, race, and insurance type.

Results identified that telemedicine introduced with the covid-19 pandemic may have reduced geographical access barriers and race may be an existing access barrier. There is a need to standardize follow-up processes within the clinic, as well as a need to gather baseline data at the state level to determine how geography, gender, race, and socioeconomic status influence access to pediatric chronic pain care.

Keywords: pediatric chronic pain, access barriers, reduce cost, improve quality of life

Identifying and Removing Barriers to Accessing a Pediatric Pain Clinic: A Quality Improvement Project

The Institute of Medicine has identified chronic pain as its own disease deserving specific, dedicated treatment (Institute of Medicine (US) Committee on Advancing Pain Research, Care, and Education, 2011). Access to adequate pain treatment is a basic human right, which means healthcare providers have an ethical obligation to provide adequate pain treatment (American Nurses Association, 2018; Carvalho et al., 2018; Cohen et al., 2020). Adequately treating chronic pain in children requires children and their families to have access to a dedicated pain management treatment center with access to multidisciplinary care (Landry et al., 2015). The biopsychosocial model explains why a multidisciplinary approach is necessary to adequately treat chronic pain in children. The biopsychosocial model explains that chronic pain is a result of the complex interplay of the following factors: biologic, sociocultural, neurosensory, behavioral, affective, cognitive, and emotional (Liossi & Howard, 2016; Miró et al., 2017). Pediatric chronic pain management centers target treatment towards each of these contributing factors by including various specialists trained in chronic pain management such as psychologists, nurses, physical therapists, and providers (Miró et al., 2017). Primary care pediatricians typically do not have the resources to provide this multidisciplinary care that children with chronic pain need to adequately return to functioning (Miró et al., 2017). Additionally, the American Academy of Pediatrics and the American Pain Society have stated pediatricians have an ethical responsibility to use a multimodal, multidisciplinary approach to reduce children’s pain (American Academy of Pediatrics & American Pain Society, 2001). For these reasons, it is important that children with chronic pain receive multidisciplinary care at dedicated pediatric pain management treatment centers.

Chronic pain is defined as pain that lasts longer than three months, is idiopathic, or is related to underlying disease (Cooper et al., 2017; Liossi & Howard, 2016). Idiopathic chronic pain in children typically manifests as headaches or pain in the abdomen, back, or musculoskeletal system (Liossi & Howard, 2016). Disease-related pain typically occurs in children with sickle cell disease, cancer, and post-operative pain that continues beyond the expected post-surgical period (Liossi & Howard, 2016). It is estimated that between 20-46% of children and adolescents around the world experience chronic pain (Landry et al., 2015). Additionally, the annual healthcare costs of treating chronic pain in children and adolescents in the United States has been estimated to be around 19.5 billion dollars (Landry et al., 2015). The economic burden of chronic pain globally is estimated to be three percent of the gross domestic product, higher than the costs associated with heart disease or cancer (Henschke et al., 2015). The high incidence and cost of pediatric chronic pain justifies the need for further investigation into ways to improve access to treatment and reduce the cost of pediatric chronic pain.

In addition to economic effects, untreated chronic pain during childhood places children at higher risk for developing chronic pain or psychologic disorders as an adult (Friedrichsdorf et al., 2016). When compared to other health conditions in adulthood, chronic pain is the highest contributor to disability and has the most negative influence on quality of life (Henschke et al., 2015). Health care providers are held to ethical standards that guide them to make access to appropriate healthcare equitable (Jonsen et al., 2015). These ethical standards can be applied to pediatric chronic pain management, supporting the need to identify ways to make pediatric chronic pain management more equitably accessible. Children and their families who face access barriers to appropriate healthcare are noted to have poorer outcomes in disease management (Marcin et al., 2016). These findings are translatable to pediatric chronic pain management, supporting the need to identify access barriers and ways to improve equitable access to care. Combining the economic burden, the negative impact on health and quality of life, as well as the ethical need for equal access to adequate treatment supports the need to identify and remove existing barriers experienced by children and their families trying to access pediatric chronic pain treatment. Removing access barriers will enhance equally available care and fulfill provider's ethical obligation to treat pediatric pain appropriately. Additionally, children and their family's quality of life will improve when the child's pain is appropriately treated using a multidisciplinary approach.

Literature Review

Literature searches were performed in PubMed, CINHAL, PsychInfo, and Ovid Medline using the search terms: "pediatric pain management," "pediatric pain," "pediatric chronic pain," "health disparities," "chronic pain," "widespread chronic pain," "widespread chronic pains," "cost," "outcomes," "access barriers," "equitable access," "access," "children," and "socioeconomic status." Literature older than five years was originally excluded. The number of primary literature relevant to the search terms was insufficient so applicable secondary literature sources were included, and the literature search was extended to include literature up to 10 years old. Two books that provided expert information guiding ethics in medicine and pediatric chronic pain management were included to fill gaps in the literature regarding ethics and equality in pediatric chronic pain management. Two position statements were included that provide national policy guidance regarding pediatric chronic pain management.

Access Barriers

Several types of access barriers were identified in the evidence preventing children and their families from accessing adequate pediatric chronic pain management care. These barriers are related to a child's geographical location, race/ethnicity and gender, socioeconomic status, and the availability of services. When children experience access barriers, they experience reduced treatment for their chronic pain, which increases the burden placed upon their families, themselves, and society related to costs and utilization of resources. In addition, children experience lower quality of life with reduced healthcare outcomes when their chronic pain is left untreated. Further exploration of these concepts will be discussed in this paper.

Geographical Location. First, geographical location is the most common source of access barriers for children and their families seeking chronic pain treatment. Researchers estimate that over 28% of children experience difficulty—accessing specialty care due to geographic location (Ray et al., 2020). Families living in rural areas experience the greatest barriers in accessing healthcare, resulting in health disparities that lead to poorer healthcare outcomes in these children (Marcin et al., 2016). In rural areas, the ratio of subspecialties to patients is 40:100,000. In contrast, the ratio of subspecialties to patients in urban areas is 134:100,000 (Marcin et al., 2016). In rural areas, the limited availability of specialty care providers creates healthcare disparities related to access for both primary care providers and their patients, requiring families to travel long distances to obtain specialty care for their child (Committee on Pediatric Workforce, 2015). Access barriers exist among children living in suburban/urban areas, but these access barriers seem to be related to socioeconomic factors in addition to the geographical location of where they live.

Race and Gender. Data surrounding race and gender access barriers for children seeking care for chronic pain is conflicting. Access barriers include potential provider prescribing and referral bias towards specific race or ethnicities. With regards to prescriptions for pain treatment, it has been reported that white children are more likely to receive opioids than minority children when treated in outpatient clinics for pain (Groenewald et al., 2018). More specifically, Black children are less likely than white children to be prescribed opioids, resulting in inadequate acute pain management among these children (Miller et al., 2019). However, the data to support this difference specifically in children being treated for chronic pain, is limited and conflicting data exists that suggests Black children are more likely than white children to receive opioids for their pain management (Miller et al., 2019). Limited data exists that providers rate pain to be higher in children who are black and/or female, resulting in higher rates of pediatric pain management for these populations (Miller et al., 2019). The limited amount of data available leaves an area of need for further exploration regarding race and related barriers to appropriate pain medication treatment associated with potential provider bias. With regards to referral patterns, females are more likely than males to be referred to a pediatric chronic pain center for care (Miller et al., 2019; Tumin et al., 2019). It is unknown if this is related to an existing bias in provider referral trends or if the incidence is higher in females in general related to biologic, psychologic and social influencing factors (Tumin et al., 2019). Conflicting data exists regarding race and referral patterns. While evidence exists supporting that Black children are less likely to be referred than white children to chronic pain treatment centers (Tumin et al., 2019), evidence also exists that Black children are more likely to be referred to chronic pain treatment centers than white children (Miller et al., 2019). Existing access barriers for females and minorities in general have been found to lead to poorer health outcomes and lower quality of life among these populations (Miller et al., 2019). The fact that existing limited data is conflicting regarding access barriers related to race and gender supports the need for further quality improvement efforts in this area to improve the quality of life in these patients.

Evidence is lacking regarding existing access-related barriers affecting children living in Oregon who require chronic pain treatment. In Oregon, there is only one pediatric pain management center available to treat children experiencing chronic pain. This multidisciplinary pediatric pain management center is located at Doernbecher Children's Hospital, an urban-based pain management center in the northwest part of the state. It is unknown whether children in Oregon have difficulty accessing pediatric pain management care at Doernbecher Children's Hospital related to geographical location, socioeconomic factors, availability of services, race or gender. Considering there are 878,938 children in Oregon (National Center for Children in Poverty, 2018), with 35% of Oregon's population in rural/frontier areas (Oregon Health and Science University, 2020), there is an opportunity to explore what access barriers exist for children and their families seeking care at Doernbecher's pediatric pain management center. Considering the recommendation that children with chronic pain should have access to pain management treatment centers for optimal return to functioning and quality of life, children should have increased and equitable access to pediatric pain treatment centers. Increased and equitable access to pediatric pain management centers for children in chronic pain may reduce the incidence of chronic pain in childhood/adolescence that persists into adulthood. Reducing the incidence of development of new pain in adulthood may reducing the high economic burden associated with adult chronic pain. Additionally, improving access to chronic pain management may improve children and their family's quality of life by preventing the negative psychologic, physical and social impacts pediatric chronic pain creates.

Socioeconomics. Existing data suggests that families from lower socioeconomic status whose children need chronic pain management incur both cost and time burdens when seeking chronic pain care for their child (Datz et al., 2019; Tran et al., 2020). These burdens include the extra time it takes to coordinate their child's care, the time they have to take off of work and the added annual out-of-pocket costs they must pay to obtain chronic pain care (Datz et al., 2019). These burdens are considered access barriers when the families lack the finances to fund the costs and/or lack the extra time it takes to coordinate care/take time off of work to take their child to a pain management clinic visit (Tran et al., 2020). The access barriers related to the extra out-of-pocket costs and time supports that families who are disadvantaged socioeconomically may experience greater access disparities. Access disparities lead to a decrease in quality of care for children with chronic pain when they are unable to function in their daily activities due to the ongoing, untreated pain (Tran et al., 2020). Removing time and cost-related access barriers could improve family's' ability to access chronic pain care, improving the quality of life for children with chronic pain. There is a need for quality improvement initiatives to identify ways to reduce the time and cost related access barriers families from lower socioeconomic status face when seeking chronic pain care for their child.

Availability of Services. In addition to socioeconomic-related access barriers, a lack of available interdisciplinary pediatric chronic pain services creates access barriers for families seeking chronic pain care for their child (Palermo et al., 2019). Services may not be readily available due to lack of dedicated multidisciplinary pain management treatment centers, delayed referral by primary care providers, lack of funding from insurance reimbursement we well as a family's ability to pay for services (Committee on Pediatric Workforce, 2015; Marcin et al., 2016; Tumin et al., 2019). Generally speaking, pediatric specialty clinics are located in urban/suburban areas (Committee on Pediatric Workforce, 2015). This creates lack of available services in many rural and frontier areas for primary care providers in these areas to refer to for specialty care, such as pain management (Marcin et al., 2016). Services may not be readily available due to a delay in referral for care and/or extended wait times once referred for pediatric chronic pain management care (Cucchiaro et al., 2017; Tumin et al., 2019). Evidence exists that children may wait in pain for an average of eight months to three years before they are referred for multidisciplinary pain management (Tumin et al., 2019). Once referred, children and their families have been noted to have waited an estimated at 6.5 months to access care provided at interdisciplinary pediatric pain management treatment centers (Palermo et al., 2019). Families report that this lengthy wait time creates increased experiences of anxiety and frustration for them and their children (Palermo et al., 2019). When access barriers related to availability of services exist, children and their families who are affected experience a reduced quality of life as their child's symptoms persist, preventing the child from returning to daily functioning (Tumin et al., 2019). This justifies the need for further quality improvement initiatives that identify access barriers to available services and innovate ways to remove those barriers. Removing these barriers can improve the quality of life for children with chronic pain by easing their ability to access appropriate treatment, helping them learn how to return to functioning in their daily lives.

Theoretical Framework

The conceptual framework within Anderson's Behavioral Model of Health Services Use (BM) was used as the theoretical framework for this project (Babitsch et al., 2012). This framework consists of three domains: predisposing factors, enabling factors, and need factors (Babitsch et al., 2012) Each of those factors contain specific individual and contextual features influencing an individual's healthcare utilization behaviors (Babitsch et al., 2012). The domains within the BM framework help explain why children in Oregon may face barriers in accessing healthcare services for pain management at Doernbecher's urban-based center and guided the data collection methods in this project (Babitsch et al., 2012). It was helpful to explore how individual and contextual features of each domain related to this project.

Predisposing Factors. Individual features of predisposing factors include demographics such as sex and age (Babitsch et al., 2012). Individual features of predisposing factors also includes social and mental elements (Babitsch et al., 2012). Social elements include such as family, while mental elements include attitudes around individual values and knowledge that influencing health care service utilization (Babitsch et al., 2012). Contextual features include those of the community such as demographics, values, and political views (Babitsch et al., 2012). The predisposing factors that relate to the evidence supporting this project include a child's gender and age (Miller et al., 2019).

Enabling Factors. Enabling factors include those influencing service utilization such as organizational structure and availability of resources (Babitsch et al., 2012). These factors also include financing available to access/support the organizational resources, both from the perspective of the payor and the payee (Babitsch et al., 2012). Individual ability to pay for the means to access services, such as the cost of travel are included (Babitsch et al., 2012). An organization's ability to fund the services through hospital fund availability and insurance reimbursement practices are included in enabling factors (Babitsch et al., 2012). Evidence supports that enabling factors may contribute to access barriers for children and their families seeking chronic pain treatment related to several concepts. These concepts include a family's type of insurance and any limiting factors this has on a child's ability to access chronic pain management services, availability of pain management treatment centers in the child's geographic location, as well as a family's socioeconomic status's influence on a family's ability to fund the out of pocket costs in obtaining chronic pain management care (Committee on

Pediatric Workforce, 2015; Cucchiaro et al., 2017; Marcin et al., 2016; Palermo et al., 2019; Tumin et al., 2019).

Need Factors. Need factors are described as the difference in an individual and provider's perceived need for healthcare. Barriers identified in the literature review that relate to need factors for this quality improvement project include referral wait times for families and delay in provider referral times related to their perceived need for care (Cucchiaro et al., 2017; Palermo et al., 2019; Tumin et al., 2019). The relatability of the individual and contextual features of the three domains to the data reviewed for this quality improvement project supports that the BM is an appropriate theoretical framework to help guide the data collection in this quality improvement project. This project aims to identify barriers children living in Oregon face when they require access to Doernbecher's urban-based pain clinic and provide recommendations for practice improvements to improve access to care.

Methods

Setting

The setting for this project was at the Pediatric Pain Management Clinic at Doernbecher Children's Hospital. Doernbecher Children's Hospital (DCH) is part of a larger organization, Oregon Health and Science University. The pain management clinic at DCH is a multidisciplinary center that treats children who are referred for services by other providers in the community, mainly primary care providers. Teams that treat children with chronic pain collaboratively include the medical team of doctors and a nurse practitioner, physical therapists, psychologists, acupuncturists and massage therapists. A team made up of a provider, a nurse, a psychologist, and a physical therapist evaluate the child's needs at the first visit. After that, the child may be referred to pain and coping clinic (psychology) and/or physical therapy, as well as receive an appropriate medication to treat their pain. Children follow-up with the specific disciplines based on individual needs. This center serves all of Oregon's child and adolescent population. Anticipated barriers included the limitations of data stored on electronic health records, the accuracy of all scanned referrals, and the availability of appropriate resources during a pandemic to do a thorough electronic health record review. Important barriers considered were the perceived importance of this work to the pediatric pain management team, the availability of staff to assist with the data collection, and the relatability of the data from a pre-pandemic time (2019) to the current effects of the pandemic on access barriers families may have faced.

Population

Inclusion criteria for the population being studied were 1) families with a child who had been referred to the Pediatric Pain Management Clinic at Doernbecher Children's Hospital from June 2019-August 2019; 2) the child had at least one initial visit establishing care; and 3) there was evidence the child had not completed follow-up visits through December 2019. This time frame was selected to avoid any bias generated from access barriers created due to the coronavirus pandemic. Evidence of incomplete follow-up was identified by electronic health record review of office visit notes specific follow-up plan in comparison to electronic health record documentation of incomplete recommended visits. Evidence of follow-up completion was obtained by telephone call to the child's family if follow-up was done locally outside of Oregon Health and Science University's electronic health record appointment documentation. Exclusion criteria were: 1) children who had been referred to the Pediatric Pain Management Clinic at Doernbecher Children's Hospital from June 2019-August 2019 and evidence existed in the electronic health record that these children completed the recommended follow-up visits through December 2019; and 2) children referred to the pediatric pain management clinic at

Doernbecher Children's Hospital outside of the project time frame of June 2019-August 2019. Estimates of referral volumes were from 3-7 patients a month. IRB determination was obtained to protect patients from harm. Additionally, children and their families could opt out of participating without any effect to the quality of care they will receive in the future at the pediatric pain clinic.

Outcomes

Implementation Procedures

This quality improvement project aimed to collect a mixture of quantitative and qualitative baseline data to understand what access barriers patients may have experienced at the pain management clinic. The quantitative data collection included completing an electronic health record chart review of demographic data and patient follow-up rates based on provider recommendations at initial new patient evaluations and was to include qualitative data collected by telephone surveys. This project was discussed with the pain management team at Doernbecher Children's Hospital and the team agreed it was important to identify existing access barriers. Team members included pediatric pain psychologists, pediatric pain physical therapists, pediatric pain anesthesiologists, and a pediatric pain registered nurse. Additionally, support was obtained from a department data analyst and biostatistician to confirm sound data collection. Findings from this quality improvement project will be reported back to the team for further discussion regarding what interventions could be implemented to improve access to the pain clinic.

Measures

Measures used to obtain outcomes were comparison of demographic data collected within a patient's electronic health record to follow-up visits attended and a proposed use of telephone questionnaires/surveys (Polit & Beck, 2017).

Demographic Data Comparisons

Demographic data collected during the electronic record review included a child's geographical location (urban or rural), race, gender, and type of insurance (private or government). Demographics mirrored existing access barriers patients faced when accessing pediatric specialty care as identified in the literature review discussed previously. The demographic data was compared against the number of recommended follow-up visits attended as evident in the electronic health record. Data was collected to track follow-up visits attended with the following disciplines: pain medication prescriber (pain MD), psychologist, and physical therapist. These visits were important to track because initial clinic recommendations included these disciplines as a part of the comprehensive chronic pain management follow-up care. Comparing the follow-up rates within each discipline with patient demographics allowed for identification of any access barriers specific to any one of these disciplines.

Telephone Surveys/Questionnaires

Proposed telephone survey data collection included a mixture of open and closed ended questions to explore common themes contributing to access barriers families faced when seeking chronic pain management care for their child at Doernbecher Children's Hospital (see Appendix A). The telephone questionnaire/survey design followed recommendations to produce high reliability and validity with limited resources and funding available (Polit & Beck, 2017). Open-ended questions were to be used to obtain richer information about why a child's provider's recommended follow-up schedule was not followed (see Appendix A). Open-ended questions can be more time consuming and costly to analyze, but they allow for access to other causes of non-adherence to recommended follow-up visits not included in the questionnaire, supporting a wider range of data collection (Polit & Beck, 2017). Having a wider range of data collection would have improved the quality of data collected to identify potential access barriers. Closed ended questions were to be used to obtain accurate descriptive statistics regarding reasons for not scheduling/attending recommended follow-up clinic visits (see Appendix A). These questions were created with the intention of discussing them with the pediatric pain clinic team, however time limitations within this project prevented the discussion from happening. The data collection measures as described above were designed to identified existing access barriers as identified within the literature and guide recommendations for future practices to reduce these access barriers.

Data Accuracy, Ethical Considerations, and Cost

Data collection accuracy was ensured. Ethical considerations for this project included protecting the rights of families to refuse to participate in the data collection without affecting their child's access to future care. Additionally, patient identity protection were included. There were no projected financial cost for this project, only the costs of time.

Implementation of Project

Project Modifications

From the initial time that this project proposal began in writing to the time of implementation of data collection, a worldwide pandemic caused by the novel COVID – 19 virus began. The pandemic required healthcare organizations to change the way healthcare was delivered by introducing telemedicine as a mainstay in ambulatory care, including in the pediatric pain clinic where data collection for this project occurred. Evidence supports that telemedicine can reduce geographical access barriers for those families living in rural locations accessing care in urban centers (Marcin et al., 2016). With this evidence in mind, it was thought that with the introduction of telemedicine at the onset of the pandemic, existing geographical access barriers may have been reduced after the pandemic for patients living in rural locations accessing urban-based care in the pediatric pain clinic for this project. To identify whether telemedicine reduced geographically related access barriers after March 2020, it was felt important to evaluate data from two-time frames: one data set from during a pre-pandemic and one data set from a post-pandemic time frame. This comparison could help identify whether there was a change in follow-up rates for rurally located patients after the onset of the pandemic with the introduction of telemedicine. The pre-covid pandemic data collection time frame was November 2019-March 2020 and the post-covid pandemic data collection time frame was November 2020-March 2021. Additionally, due to time constraints and limited organizational resources, the proposed qualitative data collection and data collection to evaluate the timing of referral to scheduled first clinic visit, were not completed as a part of this project.

Lastly, this project originally aimed to identify socioeconomic status (SES) as a potential access barrier. However, gathering enough data to determine SES was too complex for the time frame and the resources available to complete the project. As such, evaluating socioeconomic status was removed as a potential identifiable access barrier in this project. Access to care based on insurance type (government or private) was evaluated as a substitute economic-related access barrier.

Data Collection Process

Data collection began with identifying patients new to establishing care with the pediatric pain clinic as identified within the clinic's scheduled appointments from November-December of the pre-covid (2019) and post-covid (2020) time frames. Then, electronic health records of the newly established patients were reviewed to determine individual patient follow-up rates based on recommendations embedded within the chart notes. Originally, it was intended to do an electronic health record search using identified codes imbedded within the electronic health record that would reflect follow-up visits attended. However, there were no standard codes to flag a visit as an attended follow-up visit. To maintain data collection accuracy, it was necessary to do a thorough electronic health record review of all the provider clinic notes, clinic schedules, and after visit summaries provided to patients to gather follow-up visits recommended as well as those that were attended. During data collection, there were a couple of patients who fit the originally inclusion criteria of being a patient newly referred and established to the pain clinic but were being evaluated for pre-surgical anesthesia services and did not meet the original inclusion criteria. This created a new exclusion criteria for this project: patients new to the clinic for pre-surgical anesthesia evaluation. After accounting for inclusion and exclusion criteria, there were eight pre-covid patients and fourteen post-covid patient, for a total of twenty-two patients that fit the inclusion criteria (see Table 1).

Table 1

Population Distribution According to Geographic Location, Insurance Type, Race, and Gender.

Geographic Location		**Insurance Type**	
Urban	Rural	Government	Private
12	10	14	8
Race		**Gender**	
White	Black	Male	Female
21	1	5	17

Note. n = 22

Data Analysis

Data was de-identified and entered into SPSS software. Follow-up rates were calculated within each pre-covid and post-covid time-frame. These rates were calculated as a percentage by dividing actual attended follow-up clinic visits by the actual recommended follow-up clinic visit for 1) pediatric medication prescriber clinic visits, 2) pediatric pain psychology clinic visits, and 3) pediatric pain-focused physical therapy clinic visits. Bar charts were developed to represent the pre-covid and post-covid population follow-up rates (see Appendix B). The bar charts created a visual of the mean follow-up rates based on categories as potential access barriers (geographical location, gender, race, and insurance type). Low follow-up rates were viewed as a potential area for existing access barrier within each category. Higher follow-up rates were viewed as categories relating to more accessible care.

Key Findings

There were several key findings of this project. Most notably, when evaluating follow-up with the pain medication prescriber across all post-covid data set categories, there were no follow-up visits documented when medications were recommended (see Appendix B), which indicates a need to follow-up with the pain medication prescriber to evaluate medication effectiveness. This was connected to the vacancy in the nurse practitioner position reducing the availability of follow-up appointments. Due to this fact, the follow-up rates for pain medication management could not be used as accurate data to make any recommendations from. When reviewing follow-up rates by geographical location (see Appendix B, Table 2B), the post-covid data set shows a change in the percentage of rural patients accessed services, with an increase in pain psychology follow-up rates. However, little change was identified in follow-up rates within urban patients when comparing the pre-covid and post-covid data sets. When reviewing the data based on gender (see Appendix B, Table 1B) males had better follow-up with the pain psychology and physical therapy than the pain medication prescriber. Post-covid the females had better follow-up with those two services. After covid, neither males nor females followed up with the pain medication prescriber. From this data, there was no identifiable trend that pointed to an existing access barrier related to gender. When data was reviewed according to insurance type in the pre-covid population, privately insured patients had better follow-up with pain prescriber than with the Physical Therapist. As with gender, this data did not suggest that insurance type was a potential access barrier. Finally, with regards to race, there was not enough data to identify any possible access barriers. This is because there was only one Black patient, the remainder of the patients were all white. When comparing the diversity of race within the 22 patients included in this project to the Oregon vital statistics, which has a population that includes White, Latinx, Asian, Native Americans, Native Alaskans and Black, the distribution of race within this data set is not representative of the state. Due to this fact, the diversity in this data set was not sufficient to assess barriers related to race.

Data Collection Challenges

Data collection in this project was met with a few challenges. These challenges included: 1) how providers communicated recommendations to patients, 2) the location of the recommendations in the charts, 3) what the criteria for follow-up time frames was based on, 4) the impact of staffing deficiencies for evaluating patients in follow-up visits, and 5) a lack of baseline data at the organizational and state level. Some of these challenges resulted in a time-consuming search of electronic health records to determine what the follow-up recommendations were and if patients followed through with those recommendations. The lack of organizational and state baseline data made it difficult to compare project findings. These challenges will be discussed in more detail below.

Provider Communication

To start, each of the providers had a different way of communicating recommendations for follow-up within the electronic health record. Some providers' recommendations included very specific follow-up recommendations, such as follow-up in three months. Other providers were unclear, making recommendations that included the option to take the recommended pain medication or not and, if the medication was started, to update the clinic nurse in a specific time frame. A comprehensive search of patient charts was completed to ensure quality data collection and was more time-consuming than originally planned for.

Location of Recommendations

During electronic health record review, follow-up recommendations were not located in a routine, easily identified location within patient charts. Rather, follow-up visit recommendations were sometimes embedded within the body of the clinic visit notes. Other times they were only in the after-visit summary delivered to the patients. When recommendations were only within the body of the clinic visit notes, it was unclear how this was accurately communicated to patients as they do not routinely read provider's clinic visit notes. If either of these notes recommended follow-up for medication management, physical therapy, or pain psychology, the chart notes and the appointments were reviewed to see if patients attended recommended follow-up plans at the recommended intervals, when indicated.

Follow-up Time Frames

Physical therapy and psychology visits were difficult to track for several reasons. Sometimes rurally located patients followed up with local psychologists and this information was not always available within the electronic health record. In this case, time constraints of this project did not allow for the data collection when patients sought care outside of the organization that the pediatric pain clinic resided. Further, some physical therapists would recommend a set number of visits based on insurance authorization without a specific time frame for scheduling. This made it challenging to know if the patient scheduling once a month with six visits authorized by insurance was following any recommended scheduling interval (i.e. every two weeks, once a week, or once a month).

Impact of Staffing Deficiencies

In this pain clinic, pediatric anesthesiologists evaluate, diagnose and make initial treatment recommendations for patients new to clinic. Follow-up visits are primarily done by the nurse practitioner in clinic. However, the nurse practitioner was not available to see follow-up patients during each time frame studied in this project. This was because either the nurse practitioner position was vacant or the nurse practitioner had not yet been trained to begin seeing the follow-up patients. Pediatric anesthesia providers were scheduling follow-up visits with patients, but this was only in between providing anesthesia for children receiving care in the hospital operating room, and likely they were not available as much as patients may have needed for follow-up care. Without a nurse practitioner available to routinely see patients in follow-up clinic, patients were likely not able to have the option to attend routine follow-up unless it was with an anesthesia provider. This required comprehensive chart reviews to identify follow-up visits with the four different anesthesia providers. Searching patient charts for follow-up visits with the four different pain providers in the nurse practitioner absence was very time consuming.

Lack of Baseline Data

Finally, during data collection, it became evident that there was not a baseline data resource representing the project patient population at the organizational or state level for comparisons. Neither the state nor the organization collected data to determine the incidence of chronic pain in pediatric populations according to gender, race, geographical location, or insurance type. This made it challenging to know if our project findings represented the incidence within the state within these categories. The lack of baseline data was found to be a limitation considering the impact chronic pain has on functionality, even into adulthood, and given the estimated economic burden of pediatric chronic pain in the United States is estimated to be 19.5 billion dollars.

Outcomes

Findings Related to Literature

Findings of this quality improvement project that related to the literature indicate that the introduction of telemedicine due to the pandemic, may have reduced geographical access barriers. First, with the implementation of telemedicine, rurally located patients had a noticeable improvement in follow-up during the post-covid period. This supports what the literature reports that telemedicine can reduce access barriers (Marcin et al., 2016). Additionally, despite the fact that the population studied lacked ethnic diversity representative of those in Oregon, this lack of diversity itself may indicate the existence of a race-related access barriers. Specifically, it raises the question of whether the lack of diversity within this patient population reflects referral access barriers for Black children as identified within the literature (Tumin et al., 2019). However, further larger studies need to be pursued to make that conclusion.

Findings Different From the Literature

Despite that the literature identified possible access barriers related to gender (Tumin et al., 2019), this project did not identify an access barrier that was clearly related to gender. The majority of the referrals being female supports evidence that chronic pain is perceived by providers to exist more commonly in females than males (Tumin et al., 2019). However, further larger studies need to be pursued to make additional conclusions about gender-associated access barriers.

Cost Impact

The final cost impact of this project on the system was minimal, as the only cost was the time of the data collection, which was not a budgeted project within the organization.

Implications for Practice

The key findings of this quality improvement project highlight several areas of opportunity to improve future practice. First, there is a need for work standardization to document follow-up time frames within the electronic health record so they can be located easily by staff and patients. Standardizing these practices will improve patient access to follow-up recommendations and improve data tracking capabilities within the electronic health record for future quality improvement endeavors. Second, partnering with the Oregon Heath Authority to collect baseline data within the Oregon Teen Health Survey would be helpful to know if the populations studied in future quality improvement projects in this pain clinic represent the true need for pediatric chronic pain care within the communities the clinic serves. Additionally, findings from this project point to the need for continued adequate staffing to allow for patients to attend recommended follow-up visits and to explore how telemedicine may be used to remove geographical access barriers. Lastly, obtaining pediatric pain clinic team input on the findings of this quality improvement project and the impact to the clinic future practice could be helpful in determining next steps for the clinic's quality improvement projects aimed at identifying existing access barriers faced by patients.

Limitations

Limitations of this project included a small sample size of 22, unequal representation of race and gender, and staffing deficiencies that prevented obtaining an accurate reflection of follow-up rates for the pediatric pain medication prescriber. Additionally, time served as a limitation that prevented gathering of qualitative data that would have helped provide further insight into other potential access barriers.

Conclusions

The findings of this quality improvement project are useful in several ways. First, it is helpful to see that telemedicine may have an effect on improving access barriers. Second, it is very evident that keeping the nurse practitioner role filled is key to removing access barriers in follow-up rates. Also, this project highlighted how much future quality improvement work there is to be done within the state of Oregon for children. Most notably, there is a need for gathering baseline data at the organizational and state level to identify how many children/adolescents in Oregon have chronic pain and what treatments are most effective for the different types of chronic pain. This information would be helpful to track the treatments most effective at preventing adult chronic pain into adulthood. Having access to this information could have the potential to reduce the enormous economic burden that adult chronic pain plays in our society.

Summary and Next Steps

In summary, little is known about how many children in Oregon suffer from chronic pain and what access barriers exist in preventing those children from receiving adequate chronic pain care. In general, there is a significant need for future quality improvement projects that will evaluate a larger population of patients to generate a more accurate picture of what access barriers may exist for this pediatric pain clinic. Future data collection should include both quantitative and qualitative data to broaden opportunities to identify potential access barriers to pediatric chronic pain care in Oregon. Additionally, it could be helpful to present these findings to the pediatric chronic pain team caring for this population and gather input about how relevant they see this data in light of clinic current practices as well as how it would influence opportunities for practice improvements. Lastly, it would be helpful to begin partnering with the Oregon Health Authority to begin collecting baseline data from Oregon adolescents regarding the incidence of chronic pain in this population. Taking these steps is an essential start to improving the quality of care provided to Oregon’s children and adolescents with chronic pain management needs.

References

American Academy of Pediatrics, & American Pain Society. (2001). The Assessment and Management of Acute Pain in Infants, Children, and Adolescents. *Pediatrics, 108*(3), 793–797. https://doi.org/10.1542/peds.108.3.793

American Nurses Association. (2018). *The Ethical Responsibility to Manage Pain and the Suffering it Causes*. https://www.nursingworld.org/~495e9b/globalassets/docs/ana/ethics/theethicalresponsibilitytomanagepainandthesufferingitcauses2018.pdf

Babitsch, B., Gohl, D., & von Lengerke, T. (2012). Re-revisiting Andersen's Behavioral Model of Health Services Use: A systematic review of studies from 1998–2011. *GMS Psycho-Social-Medicine, 9*. https://doi.org/10.3205/psm000089

Carvalho, A. S., Martins Pereira, S., Jácomo, A., Magalhães, S., Araújo, J., Hernández-Marrero, P., Costa Gomes, C., & Schatman, M. E. (2018). Ethical decision making in pain management: A conceptual framework. *Journal of Pain Research, 11*, 967–976. https://doi.org/10.2147/JPR.S162926

Cohen, S. P., Baber, Z. B., Buvanendran, A., McLean, B. C., Chen, Y., Hooten, W. M., Laker, S. R., Wasan, A. D., Kennedy, D. J., Sandbrink, F., King, S. A., Fowler, I. M., Stojanovic, M. P., Hayek, S. M., & Phillips, C. R. (2020). Pain Management Best Practices from Multispecialty Organizations During the COVID-19 Pandemic and Public Health Crises. *Pain Medicine, 21*(7), 1331–1346. https://doi.org/10.1093/pm/pnaa127

Committee on Pediatric Workforce. (2015). The Use of Telemedicine to Address Access and Physician Workforce Shortages. *PEDIATRICS, 136*(1), 202–209. https://doi.org/10.1542/peds.2015-1253

Cooper, T. E., Wiffen, P. J., Heathcote, L. C., Clinch, J., Howard, R., Krane, E., Lord, S. M., Sethna, N., Schechter, N., & Wood, C. (2017). Antiepileptic drugs for chronic non-cancer pain in children and adolescents. *Cochrane Database of Systematic Reviews*, *8*. https://doi.org/10.1002/14651858.CD012536.pub2

Cucchiaro, G., Schwartz, J., Hutchason, A., & Ornelas, B. (2017). Chronic Pain in Children: A Look at the Referral Process to a Pediatric Pain Clinic. *International Journal of Pediatrics*, *2017*. https://doi.org/10.1155/2017/8769402

Datz, H., Tumin, D., Miller, R., Smith, T. P., Bhalla, T., & Tobias, J. D. (2019). Pediatric chronic pain and caregiver burden in a national survey. *Scandinavian Journal of Pain*, *19*(1), 109–116. https://doi.org/10.1515/sjpain-2018-0121

Groenewald, C. B., Rabbitts, J. A., Hansen, E. E., & Palermo, T. M. (2018). Racial differences in opioid prescribing for children in the United States. *Pain*, *159*(10), 2050–2057. https://doi.org/10.1097/j.pain.0000000000001290

Henschke, N., Kamper, S. J., & Maher, C. G. (2015). The Epidemiology and Economic Consequences of Pain. *Mayo Clinic Proceedings*, *90*(1), 139–147. https://doi.org/10.1016/j.mayocp.2014.09.010

Institute of Medicine (US) Committee on Advancing Pain Research, Care, and Education. (2011). *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*. National Academies Press (US). http://www.ncbi.nlm.nih.gov/books/NBK91497/

Jonsen, A., Siegler, M., & Winslade, W. J. (2015). *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine* (Eighth). McGraw Hill Education.

Landry, B. W., Fischer, P. R., Driscoll, S. W., Koch, K. M., Harbeck-Weber, C., Mack, K. J., Wilder, R. T., Bauer, B. A., & Brandenburg, J. E. (2015). Managing Chronic Pain in Children and Adolescents: A Clinical Review. *PM & R: The Journal of Injury, Function, and Rehabilitation*, *7*(11 Suppl), S295–S315. https://doi.org/10.1016/j.pmrj.2015.09.006

Liossi, C., & Howard, R. F. (2016). Pediatric Chronic Pain: Biopsychosocial Assessment and Formulation. *Pediatrics*, *138*(5). https://doi.org/10.1542/peds.2016-0331

Marcin, J. P., Shaikh, U., & Steinhorn, R. H. (2016). Addressing health disparities in rural communities using telehealth. *Pediatric Research*, *79*(1), 169–176. https://doi.org/10.1038/pr.2015.192

Miller, M. M., Williams, A. E., Zapolski, T. C. B., Rand, K. L., & Hirsh, A. T. (2019). Assessment and Treatment Recommendations for Pediatric Pain: The Influence of Patient Race, Patient Gender, and Provider Pain-Related Attitudes. *The Journal of Pain: Official Journal of the American Pain Society*. https://doi.org/10.1016/j.jpain.2019.07.002

Miró, J., McGrath, P. J., Finley, G. A., & Walco, G. A. (2017). Pediatric chronic pain programs: Current and ideal practice. *Pain Reports*, *2*(5). https://doi.org/10.1097/PR9.0000000000000613

National Center for Children in Poverty. (2018). *Demographics*. Oregon Demographics of Poor Children. http://www.nccp.org/profiles/OR_profile_7.html

Oregon Health and Science University. (2020). *About Rural and Frontier Data | OHSU*. Oregon Office of Rural Health: About Rural and Frontier Data. https://www.ohsu.edu/oregon-office-of-rural-health/about-rural-and-frontier-data

Palermo, T. M., Slack, M., Zhou, C., Aaron, R., Fisher, E., & Rodriguez, S. (2019). Waiting for a Pediatric Chronic Pain Clinic Evaluation: A Prospective Study Characterizing Waiting

Times and Symptom Trajectories. *The Journal of Pain: Official Journal of the American Pain Society*, *20*(3), 339–347. https://doi.org/10.1016/j.jpain.2018.09.009

Polit, D., & Beck, C. (2017). *Nursing Research: Generating and Assessing Evidence for Nursing Practice* (11th ed.). Wolters Kluwer.

Tran, S. T., Koven, M. L., Castro, A. S., Goya Arce, A. B., & Carter, J. S. (2020). Sociodemographic and Environmental Factors are Associated with Adolescents' Pain and Longitudinal Health Outcomes. *The Journal of Pain*, *21*(1), 170–181. https://doi.org/10.1016/j.jpain.2019.06.007

Tumin, D., Miller, R., Hakim, M., Shafy, S. Z., Drees, D., Wrona, S., Smith, T. P., Tobias, J. D., & Bhalla, T. (2019). Predictors of Referral to a Pediatric Outpatient Chronic Pain Clinic. *The Clinical Journal of Pain*, *35*(3), 205–211. https://doi.org/10.1097/AJP.0000000000000664

Appendix A

Electronic Health Record Review and Questionnaire Specifics

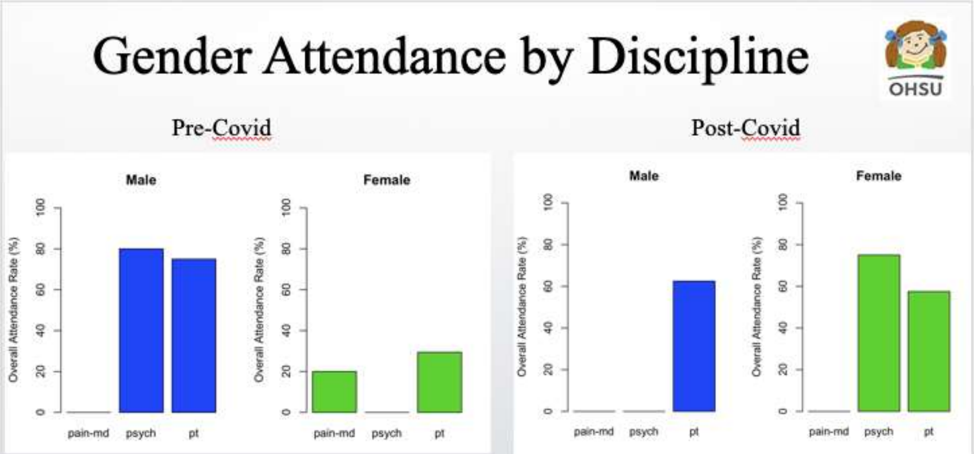
1. Electronic health record review (Polit & Beck, 2017) to identify the following variables:
    a. Children referred to Doernbecher's pain management clinic that have had one initial clinic visit with clinic notes indicating the need for continued follow-up visits.
    b. Incidence of follow-up visits scheduled as recommended by provider at initial visit.
    c. Child's geographical location: urban/suburban, rural, or frontier.
    d. Child's race.
    e. Child's gender.
    f. Child's insurance.
    g. Time from initial referral received to time of first pain clinic appointment.
2. Telephone-administered questionnaires/surveys to identify barriers in access to pain management care for children living in rural Oregon. Surveys will be performed using both open ended and closed ended questions to the caregivers of children who did not attend/schedule recommended follow-up visits. Questionnaires will be designed to collect quantitative and qualitative data regarding why rurally-based children did not continue to follow-up with the Doernbecher pain management team despite pain team provider recommendation to do so (Polit & Beck, 2017). Questioners will ask the following questions:
    a. Introduction: Thank you for being willing to talk with me today about your experience at the Doernbecher Children's Hospital Pain Management Clinic. The clinic staff is interested in getting a better understanding if there are challenges families experience with receiving care here. Thank you for being willing to talk

with me today about your experience at the Doernbecher Pain Clinic. The clinic staff is interested in getting a better understanding of the challenges families experience with receiving care here. Last year when your child was seen, the team recommended follow-up visits, do you mind if I ask you about them so we can help provide better care for you and future families?

b. Your family's identity and response will be kept confidential and your responses will not affect your child's future care at our clinic, but will be used to improve the care we provide for your and future families.
c. Based on the first clinic visit, do you recall the recommended follow-up visits that were discussed?
d. What information can you share with me to tell why your family was unable to schedule the recommended follow-up visits as discussed in the first office visit?
e. What would have made it easier to attend the recommended follow-up visits at Doernbecher pain clinic for your child?
f. Did your child's pain resolve on its own before the follow-up visit?
g. Did your family experience financial constraints that limited your ability to travel to Doernbecher for the office visit?
h. Did you feel Doernbecher was located too far for your family to travel to for a clinic visit?
i. Did you feel the follow up visit was valuable to reducing your child's pain?

Appendix B

Table 1B

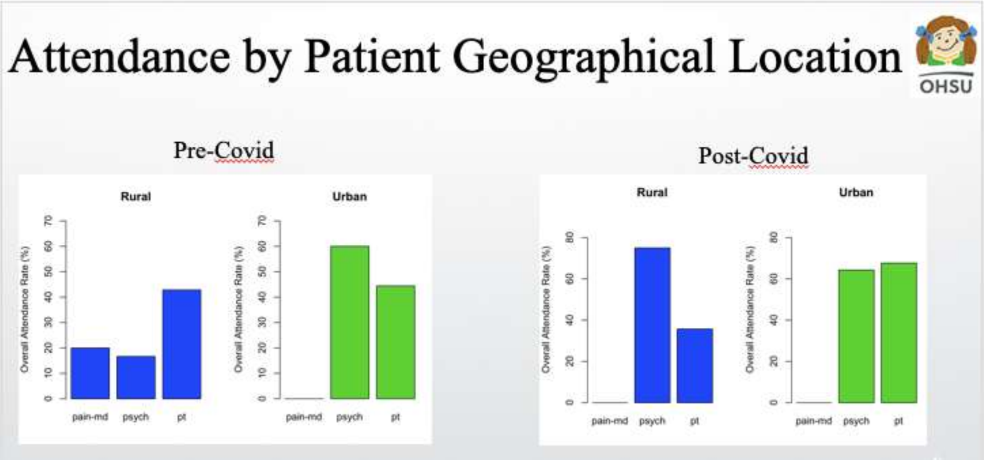


Gender Attendance by Discipline

Pre-Covid

Post-Covid

Table 2B

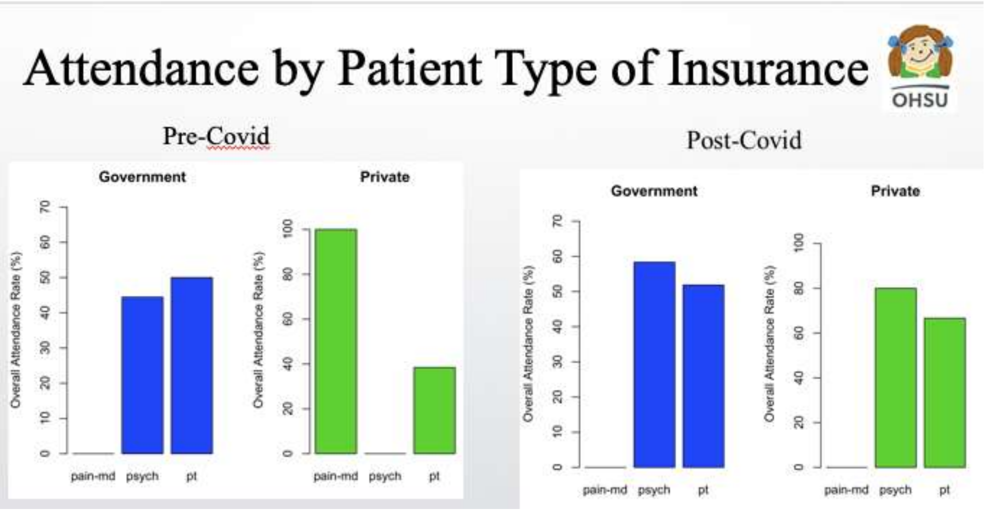


Attendance by Patient Geographical Location

Pre-Covid

Post-Covid

Table 3B



Attendance by Patient Type of Insurance

Pre-Covid

Post-Covid